



June 19, 2002

TO: California HMO Executives

FROM: Joy O. Higa
Deputy Director for Plan and Provider Relations

SUBJECT: HMO Coverage for Phenylketonuria (PKU)

It has come to the attention of the Department of Managed Health Care that health plan enrollees with the condition phenylketonuria (PKU) have encountered procedural barriers in obtaining coverage for treatment mandated by SB 148, which added Section 1374.56 to the Knox-Keene Act. This memo is to clarify HMOs' obligations with respect to the coverage of PKU.

Reported consumer problems. Problems reported by consumers include:

- HMO procedures requiring enrollees to first purchase medically necessary formulas and special food products and then request reimbursement from the plan;
- Inappropriate delays in reimbursing the costs of special foods and formulas;
- Lack of knowledge among plan personnel regarding coverage for PKU supplies; and
- Patterns of providing coverage only after enrollees dispute a denial of services.

Required coverage for PKU. Plans must provide coverage for the testing and treatment of PKU as mandated at Section 1374.56. Coverage must include the provision of formulas and special food products that are part of a diet prescribed by a licensed physician and managed by a health care professional, in consultation with a physician who specializes in the treatment of metabolic disease. Coverage is required when the special diet is deemed medically necessary to avert the development of serious physical or mental disabilities or to promote normal development or function as a consequence of PKU, and to the extent that the cost of the necessary formulas and special food products exceeds the cost of a normal diet.

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Compliance with the PKU mandate. In order to ensure that plans comply with this statutory mandate, plans should:

- Have written policies and procedures establishing criteria for PKU testing and treatment;
- Ensure that unreasonable barriers to access are eliminated;
- Ensure that communications to enrollees, including evidences of coverage and subscriber contracts, explain how enrollees may access the benefit; and
- Adequately train staff to provide services and timely and accurately respond to questions or complaints regarding PKU coverage.

The Department may further survey HMOs in the near future to determine full compliance with the PKU mandate. If you have any questions, please contact your licensing counsel.